Arizona Department Of Health Services

Office For Children With Special Health Care Needs

INTEGRATED SERVICES FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS TASK FORCE

TASK FORCE SURVEY RESULTS

FEBRUARY 16, 2006

WHAT DOES "INTEGRATED SYSTEMS OF CARE FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS (CYSHCN)" MEAN TO YOU?

- A clear path for CYSHCN to receive comprehensive, coordinated care with a medical home approach
- One application and eligibility process; one lead agency or agencies with defined service centers; cohesive and accessible information; family support; and access to services.
- Collaborative care with communication, seamless service deliver, and cross training between multiple service systems for the benefit of the patient's health status and quality of life.
- Regardless of the patient's diagnosis, where in the state they are residing, or who their payor of health care, a cyshcn can access the healthcare system, "have seamless" service (i.e., have a minimum of obstacles to healthcare for both primary health care and specialty services), can expect the various providers to communicate with each other and to coordinate their services to minimize appointments, procedures, etc.
- No duplication of paperwork/processes and good communication between all agencies/parties involved.
- It means that children receive services that they need to obtain their optimum development within their family and community.
- An integrated system of care for cyshcn promotes families' capacity to support and enhance their child's enjoyment of and participation in primary care giving relationship and the daily routines and activities of their family and community. An integrated system of care for cyshcn recognizes the interrelated aspects of children's social, developmental, medical, and educational needs, accesses the appropriate expertise and resources to support and respond to families' informed decision-making and always focuses on capacity building and independence, rather than dependency-creating as is the case with some traditional approaches.
- Systems that touch the lives of cyshcn work together for the betterment of the children and youth.
- Opportunity to include child care and health into the integrated system for cyshcn.
- Seamless social, financial, and physical care that incorporates traditional and complementary care.
- Organizing services at the state and community levels so that families can use them easily.
- A statewide system that allows all children and families the ability to access and receive the services to address their health care needs. An integrated system will remove any barriers which would prevent or make it difficult to receive needed services.
- It means all systems of care for children and youth in AZ should be accessible to cyshcn and their families. There should be an emphasis on interagency communication and resource sharing to address their needs and ensure quality services.
- Integrated Systems of Care for Children and Youth with Special Health Care Needs means that everyone who works with these children and families and provides services to them would know each other on the community level and on the state level. It means that we would work together to improve the current systems and develop collaborative relationships that are needed to remove barriers and work more cohesively together.
- No response = 3

	Total Responses	Strongly Agree and Agree	Strongly Disagree and Disagree
There is a need to integrate services for cyshcn in Arizona	15	93%	7%
The biggest challenge to the integration of services for cyshcn is the structure of state agencies.	11	64%	36%
The biggest challenge to the integration of services for cyshcn is the lack of time.	12	17%	83%
The biggest challenge to the integration of services for cyshcn is the lack of money.	12	25%	75%
The biggest challenge to the integration of services for cyshcn is the lack of a plan.	12	100%	0
The biggest challenge to the integration of services for cyshcn is the resources to devote to the issue.	11	58%%	42%
The biggest challenge to the integration of services for cyshcn is a lack of understanding of the issues.	13	77%	23%

WHAT IS THE BIGGEST CHALLENGE TO THE INTEGRATION OF SERVICES FOR CYSHCN?

- No Response = 3
- Don't know = 1
- Excellent service coordination.
- The systemically created silos of care have limited systemic reward to collaborate with service providers from different silos.
- …a combination of factors including the lack of incentives and a failure to use a "systems approach" to a complex issue and milieu.
- Commitment to make the changes.
- Resources and a plan.
- The will to do so by all partners—if we put children and families first, we can do great things.
- Making integration easy through knowledge of resources and billing for care continuity services.
- Different payers, shortage of providers, and parochial perspectives.
- The availability of family-centered care coordination for all families.

- Collaboration between agencies, RHBAs, and providers.
- The ability to provide equitable services to remote regions of the state.
- The usual territorial issues and lack of collaborative relationships.

WHAT IS THE BIGGEST ASSET/STRENGTH IN THE STATE OF ARIZONA THAT CAN BE UTILIZED TO DEVELOP AN INTEGRATED SYSTEM OF CARE FOR CYSHCN?

- No response =2
- There is already a major program (CRS) that integrates specialty care for a large number of cyshcn.
- Commitment to the task.
- Leadership qualities (in family serving organization and state agencies).
- Strong leadership advocacy of children from the Governor's Office.
- Multiple state, local, and other (such as IHS) organizations that have collaborated previously and are willing to collaborate on this issue.
- Support of the Governor and Agency Directors.
- Collaboration in committees.
- Organized and committed families.
- Leadership of OCSHCN.
- People who want it done.
- Knowledgeable people.
- A desire from the Governor and State Department directors to develop an integrated system of care for children.
- The willingness of diverse groups of people and agencies to define the issues and develop an action pan.
- To my knowledge and experience, I would say that CDI is the biggest asset because it has got some of the players already working together very well.

OTHER COMMENTS RELATED TO THE DEVELOPMENT OF AN INTEGRATED SYSTEM OF SERVICES FOR CYSHCN.

- No response = 12
- We need to figure out how to bring Education into the collaborative circle.
- The integrated system should include all cyshcn.
- AHCCCS is a secondary biggest asset.
- Three part answer:
  - Will require improved coordination and sharing of health information;
  - Will require adoption and utilization of current and future technology; and
  - Should be "patient/family-centered.

WHAT SERVICES DO YOU THINK SHOULD/COULD BE INTEGRATED TO PROVIDE MORE EFFECTIVE SERVICES FOR CYSHCN?

- No response 2
- Primary care should be integrated more effectively with specialty care; behavioral health care should also be integrated more effectively for this population.
- Medical with non-medical
- Eligibility process, one lead agency, coherent and easily accessible information, interagency training on team concept/model.
- Medical and behavioral providers would be beneficial in not only creating positive patient outcomes in the area of functionality and quality of life, but it would create a positive medical cost offset for our third party payors.
- Primary care, specialty services, medical equipment/medical devices, school needs/services, community resources, and job training.
- Better care coordination/supervision at the PCP level (truly oversee care provided by various specialists and make sure they are connected to each other. Have one primary case manager to coordinate necessary team meetings between agency representatives.
- Medical, educational, and mental health.
- Children's Rehabilitative Services (CRS) should be integrated into mainstream health care system.
- Child Health Care Consultation to provide cshcn to attend child care and preschool, and communication between health providers and child care.
- Medical and mental health programs; allow parents to choose health care options; and education regarding the challenges families face.
- Each family has its own unique needs and resources—therefore, care coordination is a key ingredient for integrating services for an individual family.
- Mental and behavioral health.
- Health care and education.
- Education is key to success of integrated services. Our children are in school 6 hrs a day. They need to work more collaboratively with all the other partners. This happens at the community level better than at the state level, but they still have an attitude of not needing to work with others. For example: The PT, OT, or Speech that a child receives at home is suppose to be "medically necessary," but to work best for the family, sometimes it is important for both to work towards one essential goal. It makes it so much easier on the family if they will communicate and work together on collaborative goals. The progress a child makes will be increased.

DOES YOUR ORGANIZATION HAVE A PHILOSOPHY REGARDING INTEGRATED SERVICES FOR CYSHCN?

- Yes 8 (47%)
- No 6 (35%)
- No Response 3 (18%)

IF YES, HOW IS THAT PHILOSOPHY ARTICULATED?

- We have a general mission and principles of practice that focuses on all the children and families we serve.
- Mission, strategic plan, MOUs, and other agencies.
- We have integrated behavioral health services provision in our primary care facilities and we have created systemic avenues of communication and ease of ingress for mutual patient pools. This endeavor has created a positive infrastructure for continued growth in the area of integration.
- Families must be actively included/involved in all treatment planning. Child and Family Teams are meant to identify all needs, including therapy, medical, etc., and include all pertinent players.
- DES' entire delivery system is being reengineered around service integration, cyshcn and their families can be a beneficiary of the many services that DES provides—to assist families to thrive and remain intact—including TANF cash assistance, family support, child care, etc.—these services assist families with children with special needs---broader than just their medical needs. Also, for cyshcn and DD, their acute and long term care are integrated into our system.
- See SARRC's mission statement.
- Families must be equal partners in decision making at the family, community, state, and federal levels.

DOES YOUR ORGANIZATION HAVE ANY ACTIVITIES THAT FOCUS ON THE INTEGRATION OF SERVICES FOR CYSHCN?

- Yes 11 (65%)
- No 4 (24%)
- No Response 2 (12%)

IF YES, PLEASE INDICATE WHAT ACTIVITIES, FUNDING SOURCES, AND ANY PARTNERS YOU MAY HAVE.

- We have been able to provide on-site specialty services for some conditions such as a pediatric neurology clinic and a genetics/dysmorphology clinic (at the Phoenix Indian Medical Center consistent with the concept of a "medical home.")
- Multiple part answer:
    - The intent of the Child Find program is that all children from birth through age 21 with delays or disabilities are identified, located, and evaluated to receive the supports and services they need. Public schools and the Arizona Early Intervention Program are responsible for "finding" eligible children and providing services needed for them to reach their developmental milestones or meet their educational needs.

  - Comprehensive Systems of Personnel Development (CSPD) administer a wide variety of training opportunities for school staff that directly supports students with disabilities.
  - The Early Childhood Special Education (ECSE) Preschool Unit is a part of the Arizona Department of Education, Early Childhood Education Unit. The ECSE Preschool Unit provides leadership and direction through collaboration with a variety of interested parties. We work to ensure quality educational services for children with disabilities, ages 3-5 years. We provide support and technical assistance to schools, early childhood special education staff and families of young children.
  - Parent Information Network provides information and resources to enhance parent involvement in the special education, including issues related to LRE, referral, and a limited amount of disability-specific information.
  - Arizona has provided and maintained a Special Education Advisory Panel (SEAP) for the purpose of providing policy guidance with respect to special education and related services for children with disabilities.
  - The SUPPORT Cadre offers peer consultations in regular education, special education, administration, psychology, and other related areas to districts to improve services to special education services.
  - The transition Services Section works with students, families, school personnel, and other state agencies to address the issues of transition planning beyond high school.
- We host the Utah's Universal Application System and assist other states to create a similar streamline application process for families.
- Currently we have an initiative to provide integrated health care for children with autism.
- DBHS is working with DDD to have one functioning team, rather than separate child-family teams (DBHS) and ISP (DDD).
- We are currently in the 2nd year of a two-year HRSA planning grant that is directly linked to the integration of community systems with our Pediatric Department in South Phoenix. It has been a positive planning period with a powerful collection of community stakeholders. The specificity of "cyshcn" would tie in well with our programming if the planning efforts evolve into implementation.
- In Colorado we focused on integration of services with Part C, primary care, and the schools, especially for transition. We have big goals to work more closely with EPSDT/Medicaiid.
- Partnership with the Title V agency.
- We have contracts with AzEIP and DDD trying to accomplish integration of all children with disabilities or special needs.
- Multiple part answer:
  - Development of the statewide Child Care Health Consultant Network
  - Funding is very sporadic, through grants.
  - Partners include: County Public Health Departments, ADHS/OWCH, United Way, Southwest Human Development
- Our Community Action Team meets monthly to talk about issues facing families in our community. A lot of the conversation is about children and youth with special

needs. Because we have all of the community partners at the table, we can develop a preventative philosophy which works to eliminate problems from the start. For example: Our local behavioral health clinic has placed a therapist in a local medical clinic 2 days a week to try to help integrate those services.

- DES is redesigning major components of the Arizona Early Intervention Program (AzEIP) which is the State's interagency system of services for children, birth to three, with developmental delays or disabilities and their families. DES is integrating services from a structural and programmatic perspective. Structurally, DES is consolidating service delivery contracts currently administered through DES' Division of Disabilities (DDD) and Arizona Early Intervention Program (DES/AzEIP). Programmatically, the redesign will promote integrated, cross-disciplinary team-based practice that focuses on functional, meaningful outcomes as defined by the family. DES continues to work with Arizona State School for the Deaf and the Blind (ASDB) and the Department of Health Services, Office for Children with Special Health Care Needs (ADHS/OCSHCN) to define their role in the system redesign, both structurally and programmatically. Arizona Department of Education (ADE), the Arizona Health Care Cost Containment System (AHCCCS), and the Interagency Coordinating Council (ICC) are critical partners in addition to ASDB and ADHS/OCSHCN. The redesign impacts services funded by Part C of the Individuals with Disabilities Education Improvement Act (IDEA), Arizona's Long Term Care System(ALTCS), and state funds. The Vocational Rehabilitation program focuses on the integration of services for youths to help them in obtaining employment. RSA has Intergovernmental Agreements with Juvenile Corrections and Department of education Exceptional Students. VR counselors work closely with Special Education Coordinators from the various school districts (including charter schools) throughout the state assisting students with disabilities in transitioning from school to work. VR Counselors work closely with Juvenile Corrections staff providing services to youths with disabilities that are being released from the correctional system. Just recently RSA has begun to provide services to youths that are in foster placements.

PRACTICAL ACTIVITIES FOR THE TASK FORCE:

- To ensure that the Task Force's activities do not duplicate existing initiatives, the Task Force could identify and review existing service integration initiatives and strategies to support, expand, or coordinate initiatives. The diverse representation of the Task Force also provides an ideal forum for brainstorming new or emerging opportunities to design and implement service integration strategies.
- All members of the Task Force should be taught the Community Development philosophy.
- Coordinate services across agencies.
- Single application and eligibility process; one lead agency or agencies with defined service centers; coherent and easily accessible information; and accessibility to services.
- Develop effective and accurate measures to assess service integration—disseminate this information to stakeholders.
- The development of a streamlined process for families to apply for services, such as the Universal Application System in Utah.

- Establish an efficient method of compiling and disseminating information about AZ systems of care to private and public agencies, consumers, and the public at large.
- Break down the medical mental health barrier.
- Determine what integration means—what would be different?
- Develop a protocol and IGA amongst state agencies for the delivery of services to cyshcn.
- Map the current system in a simple display/format that clearly describes existing services and responsibilities and identifies gaps and/or potential areas of integration focus.
- Work through a "failure mode and effects-type" analysis to identify where there are obstacles currently for cyshcn and their families.
- Identify resources (such as referral options and financial resources) to assist in the process of integrating the services for cyshcn.
- Identify community (both geographic and health care community) strengths that can be useful in exploring this issue.

WISHFUL ACTIVITY FOR THE TASK FORCE:

- More Community Action teams would be established in other communities around Arizona.
- Wishful activity includes strong and creative measures to allow the dollars to follow the patient rather than the patient traversing multiple systems in a fragmented way. Think and plan well in the area of reimbursement for service delivery structure.
- Have electronic database/medical record/general record for all involved agencies to have access to and add to.
- Empower parents to take control over their child's care.
- The Integrated Task Force will present to the Governor a broad plan for building upon the strength of the current activities. The plan would be instrumental in allocating resources to met the needs of cyshcn and their families.
- Streamline funding for services to remove barriers.
- Explore the use of telehealth modalities as well as other new technologies (electronic medical record) as part of the solution. Would suggest exploring both technologies and soon-to-be-released.

TO MAKE THIS TASK FORCE SUCCESSFUL……

- It will take a concerted effort
- It will require collaboration
- It will require input from the cyshcn and their families
- Leadership needs to simplify the identification of the issues, avoid political conflict, and focus on reachable objectives.
- Have achievable outcomes and adequate staff support.
- Timely, clear, purposeful communication about Task Force Initiatives will encourage participation and keep the momentum going.

- A continuous quality improvement model needs to be promoted by building partnerships, collecting baseline data, developing an action plan, implementing the plan, and measuring the results.
- Give it teeth, i.e., the power to enact change.
- We must get support from involved agencies when it comes to making necessary changes and changing operations—even when it may be uncomfortable for some folks.
- I will stay devoted to the cause of integration and collaboration which can transcend systems of care.
- We need to share a common goal for the Task Force.
- It needs to make concrete measurable steps to complete ----------??????
- We have to have meaningful participation and firm commitment from all partners.
- Task Force members must have a clear and consistent vision for service integration, knowledge of the current initiatives and strategies to support and facilitate current initiatives and opportunities to identify new collaborative initiatives. In addition, participants all need "take away" action steps to better integrate their agencies around special needs health care.

MY VISION OF THIS TASK FORCE IS……..

- that some improved integration of the health care system for children and youth will result.
- that it will improve the relationships at the state level so that things can work more smoothly at the community level. State level people will try to see that the things they do everyday have either a positive or negative effect in communities across Arizona.
- not set at this time.
- that there be progress on the creation of one application and eligibility process, that there is one lead agency or agencies with defined service centers, that there is coherent and easily accessible information, that there is family support and access to services.
- success for the benefit of our targeted population and for the health of the system itself.
- to be able to take steps toward actually accomplishing what many different agencies have talked about, dreamed about.
- to develop a statewide interagency model for helping families apply for services through an interagency application process that is non-duplicative.
- still evolving.
- to develop a framework of action for all local and state agencies, providers, and families to ensure that youth and children receive timely services to address their health care needs.
- to see the group effectively describe the current system of care, and clearly delineate where integration might make care better (integration for the sake of integration, I hope is not the intent of the Task Force), and then define steps to implement that integration.

- to describe a vision of an integrated system that responds to the needs of cyshcn (with emphasis on improving "transitions"); to identify current obstacles to better access and integration to health care and community services; and to provide a plan to overcome the obstacles and achieve an integrated system (in the state of Arizona).

I SEE MY ROLE IN THIS TASK FORCE AS……..

- bringing the broader perspective of service integration across a broader child and family and community vision, access to resources and DES and new funding.
- the person who can represent families and communities. I share the perspective from the community level and help to build the relationships that will be vital to the success of the grant.
- a community collaborator.
- facilitating family involvement.
- listening and learning and sharing experiences.
- providing information about the success and barriers that have been evident in our own ventures, as well as offering MPHC collaboration to our mutual efforts.
- ensuring that behavioral health needs of cyshcn are available, accessible, able to merge with other agencies as needed, and are of high quality.
- provide integrative developmental pediatric perspectives as it pertains to autism and related disorders.
- a member and a subcommittee member.
- to initially learn about the mission and activities of the Task Force, as well as become acquainted with the membership and then fulfill my responsibilities as defined by my role.
- helping to keep connection with children's systems.
- as identifying the challenges and barriers for children and youth involved in the juvenile justice system from receiving health care services.
- sharing what knowledge and expertise that I may have that is pertinent.
- providing input from the perspective of American Indians in Arizona, as well as those who reside in rural areas (including constraints such as transportation [no car] or communication [either no phone or no phone service] and providing ideas and feedback on proposals.

WHAT RESOURCES COULD YOU OR YOUR ORGANIZATION BRING TO THE TASK FORCE?

- Mostly time and advice; also the perspective of a general pediatrician, information about the Indian Health Service and some general information regarding our population and their needs.
- My organization will allocate some of my time, and some of my staff's time to participate in the Task Force and related activities. It is unclear to me what further resources might be necessary.
- $38,000 to pay parent leaders. Funds must be spent by 6-30-06.
- Participation and staff resources.

- My participation in Task Force activities (meetings, e-mail communication, etc.) and dissemination of Task Force information to the appropriate ADE/EES staff and programs.
- Facilitation of an on-line interagency application process.
- Parent support, meeting place, and lobbying.
- Expertise of child/adolescent psychiatrists, best practices around behavioral health care, experience with collaborative efforts with DDD and CPS, experience with infants/early childhood behavioral health needs/risks/assessments.
- Primary care venue for all of the community, insured and uninsured. This currently includes dentistry, vision center, radiology, WIC, asthmatic educators, and behavioral health practitioners.
- Distribute information to families and represent family/consumer voice.
- Expertise in early childhood.
- Time, expertise, commitment, experience, vision, relationships, and enthusiasm.
- DES bring the expertise and representation of many programs that impact families and their young children with special health care needs, in addition to the daily experiences of managing the health care needs of children and youth with Developmental Disabilities. Vocational Rehabilitation receives 21.3% state appropriated funds and 78.8% federal match. VR staff has expertise of the different types of disabilities, information/resources on assistive aids and devices and we are already partnering with ADHS, Department of education, WIA/One Stop Centers, Universities, and Juvenile Corrections, etc. We also work closely with Independent Living Centers.

- **WHAT DOES A COMMUNITY BASED SYSTEM OF CARE MEAN TO YOU AND YOUR ORGANIZATION?**
- All families and communities have strengths and resources. Resources of the family (such as extended family, neighbors, insurance, etc.) and community (i.e., faith-based groups, schools, etc) are primarily utilized to address the needs of the family. The role of more formal supports, such as state programs and resources may be time limited and directed toward supporting/expanding the capacity of informal supports to meet the needs of community members and/or remove barriers to accessing or benefiting from existing family and community resources. Community-based systems of care integrates formal and informal supports at a local level to facilitate accessibility, ensures that informal supports are maximized, and all supports are responsive to the unique cultural, demographic, and geographic needs of the community and maintains the focus of promoting integration into and independence within the community.
- They are the systems of care that families use everyday in a community. The local school district, the local medical clinic, the local therapist, the local behavioral health clinic, etc.
- Local communities coalesce to identify their specific needs to improve child health and access to quality childcare and jointly apply for resources needed to accomplish needs.
- Community based means that families have access to high quality services appropriate to the needs of their children wherever they live.
- Cost effective, consumer driven, and designed to meet local/individual needs.
- Close to families.

- Innovation in serving a population by providing a one-stop shop for enhanced health outcomes and utilizing the strengths of the surrounding community systems in collaboration with their own.
- Families/children are able to access all needs in their immediate community with focus on in-home services when support services are needed. People should not have to travel to Phoenix for quality healthcare.
- Care that takes place by choice of the family and community, not by state mandate or hospital boards.
- Families can access what they need close to home.
- As the lead education agency in the state, ADE/ESS relies on it's relationship with public education agencies, families, and other community partners to serve students with disabilities. Community-based systems of care mirror that commitment.
- Locally controlled and operated.
- The ADJC's vision is safer communities through successful youth. A community-based system of care would address a youth's health needs and assist him/her in being successfully reintegrated back into the community from a secure care facility.
- The provision of health care and/or other supportive services in locations other than hospitals.
- Systems that are locally based and locally organized.

WHAT TYPES OF SERVICES SHOULD BE COMMUNITY-BASED? WHY?

- Many of the services that are needed on a daily basis; most of the primary health care and support and as much of the specialty services as possible. In my opinion, from a patient perspective, two limiting factors in obtaining services are time and money. It would facilitate access and delivery of services if it could be done locally to the greatest extent possible. Furthermore, it would facilitate the integration of cyshcn into the community.
- Primary care, recreation, respite
- Behavioral and mental health treatment. Our Department is realizing a significant increase in youth who have behavioral and mental health problems, as well as substance abuse and sexual acting out problems. Research indicates that addressing these issues is more effective in community-based programming than in a secure setting.
- Family-specific services
- Avoid the need for institutions such as ICF-MRs and skilled nursing facilities. Provide medical services in the family/foster home (trach., vents, suctioning, tube-feedings, etc. by nursing staff when needed.
- I can't think of any that should be excluded.
- Primary care, specialty care (as much as possible), early childhood and schools, transition services and support.
- Social services, medical services, and all family supports.
- Actual delivery of programs/services should be community-based. Better fit.
- As many services as possible should be community based so that families don't have to travel large distances to get care for their child and so that the family can remain together. We know with the rural nature of much of Arizona that specialty" services are usually

not going to be delivered in the local communities, but if normal everyday services could be available in every community in Arizona, that would be a vast improvement.
- Children should be afforded every opportunity to remain in their own communities for all services.

DOES YOUR ORGANIZATION CONDUCT A FORMAL NEEDS ASSESSMENT OF THE COMMUNITY AND/OR INDIVIDUALS YOU SERVE?

- Yes 11 (65%)
- No 3 (18%)
- Not Applicable 2 (12%)
- No Response 1 (6%)

IF YES, HOW OFTEN DO YOU CONDUCT A NEEDS ASSESSMENT?

- Annually 2 (18%)
- Every 3 years 1 (9%)
- Every 5 years 2 (18%)
- Episodic 3 (27%)
- No time frame specified 3 (27%)

IF YES, ARE THERE RESULTS SPECIFIC TO CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS?

- Yes 9 (82%)
- No 1 (9%)
- No Response 1 (9%)

IF YES, CAN THESE RESULTS BE SHARED WITH THE TASK FORCE?

- Yes 9 (82%)
- No 1 (9%)
- No Response 1 (9%)

DOES YOUR ORGANIZATION HAVE A STRATEGIC PLAN?

- Yes 15 (88%)
- No 0
- No Response 2 (12%)

IF YES, DOES YOUR PLAN SPECIFICALLY ADDRESS ISSUES RELATED TO CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS?

- Yes 10 (67%)
- No 4 (27%)
- No Response 1 (7%)

IF YES, DOES YOUR PLAN ADDRESS THE INTEGRATION OF SERVICES?

- Yes 7 (47%)
- No 7 (47%)
- No Response 1 (7%)

COMMENTS REGARDING THE STRATEGIC PLAN:

- At this time I am unable to provide specific information about how issues related to special education students may differ in the plan from what federal and state l aw mandates.
- A copy is available at your request.
- Through Child Care Health Consultants child care providers can help identify a plan of care to enable children with special needs to attend child care. Physicians are being encouraged to use a nationally validated screening tool (PEDS) to identify children needing early intervention to maximize their individual potential. Mental health consultation is recognized as a tool for prevention through treatment. Reimbursement needs to allow use of the DC:0-3 coding scheme to ensure very young children are adequately treated.
- The SFY 2007-2011 Five Year Strategic Plan addresses issues related to children with special health care needs: Goal 2: To improve the well-being of children, adults, and families by increasing permanency and stability for children in the welfare system, individuals with developmental disabilities, those at risk for homelessness, victims of domestic violence, and the elderly. The performance measure specifically related to cyshcn under this goal is: Increase the number of children and families who participate in case planning that includes the provision of services to meet the child's behavioral health, medical, and educational needs. The Department's service integration focuses on the holistic approach to serving families and would include issues related to cyshcn.
- Our strategic plan has several goals that address working closer with other child serving organizations and stakeholders in order to integrate services.
- While we do not have a goal specifically related to integration, it is our goal in all the services we provide.
- Our plan addresses the need to strengthen existing services and develop the strengths of the community and its members so that it increases the quality of life for cyshcn. We work hard to build collaborative relationships with all service providers and agencies so that they will work well together. We have seen significant progress in this area.

WHAT TYPE OF DATA DOES YOUR ORGANIZATION COLLECT REGARDING THE CHILDREN AND YOUTH SERVED BY YOUR ORGANIZATION?

- No Response/Not Applicable = 4
- Our data is based on what is already collected by the state: SLAITS data, AHCCCS encounter data, AzEIP enrollment, etc.
- Our Research department collects extensive data on our youth.
- Service/encounter data and cost data
- Diagnosis age ethnicity, presenting issues

- Demographic information including age, sex, community of residence, insurance/third party payment information. Ambulatory visits such as diagnoses and number of visits, hospital data, laboratory results, radiological studies, and some vital statistics (but usually by "area which usually does not correspond to county or state boundaries).
- DDD: demographic data, services used. Healthcare is tied up in encounters and QMACs was not able to analyze health plan data.
- The Division of Children, Youth & Families collects child-specific information on children and youth in our care, custody, and control. This information includes demographic information about the child and some information as to the child's special needs which could include physical and behavioral health needs of the child. The non-demographic information are in non-mandated fields in our automated system which translates into under reporting of this information.
- We select data based on a specific research question that is being asked.
- Colorado Child Health Survey
- Diagnostic prevalence/frequency of service provision

CAN YOU DIFFERENTIATE CYSHCN IN YOUR DATA?

- Yes 10 (59%)
- No 3 (18%)
- No Response 2 (12%)
- Not Applicable 2 (12%)

CAN YOU GENERATE REPORTS ON DEMAND OR AT FIXED INTERVALS?

- Yes 10 (59%)
- No 1 (6%)
- No Response 5 (29%)
- Not Applicable 1 (6%)

CAN YOU SHARE THESE REPORTS WITH THE TASK FORCE?

- Yes 6 (35%)
- No 3 (18%)
- No Response 7 (41%)
- Not Applicable 0

COMMENTS REGARDING DATA SHARING:

- We could possibly share aggregate data, but there have been many issues about sharing data with agencies outside of Indian Health Service, including data with tribes. I think it is possible, but I am reluctant to say yes. On the other hand, we have just started electronically exchanging immunization data with ASIIS, so data sharing is possible.
- As long as our guidelines are followed.

WOULD YOUR ORGANIZATION HAVE AN INTEREST IN MERGING YOUR DATA WITH THAT OF ANOTHER ORGANIZATION?

- Yes 6 (35%)
- No 1 (6%)
- No Response 9 (53%)
- Not Applicable 1 (6%)

IF NO, WHY NOT?

- The state has access to much larger and more comprehensive data sets.
- It would depend on what the data is and what the purpose would be and if it didn't violate confidentiality laws that we are bound to by our contracts.
- This topic needs clarity. For what purpose would data be merged? Is "like" data available.
- I would personally; from the perspective of the organization it would probably depend upon the anticipated benefits of such a merger of data. Again, our data is collected based on "areas" and does not lend itself to be easily merged with state or county data or other databases. In general, tribe-specific information is not released without the consent of the tribe.

IF YES, WHAT QUESTIONS WOULD YOU BE INTERESTED IN ASKING OF THE DATA?

- Unsure at this point
- I am specifically interested in receiving medical cost offset information that would be derived across multiple systems of health care.
- Cost data, service distance data, deep end costs vs. upstream preventative costs
- Not sure at this point, but it would be interesting to know how much (what kind and how valued and to how many) primary and/or secondary care was provided to CRS enrollees by the counterpart AHCCCS health plans. I would have the same interest in knowing what and how valued the extent of behavioral health services provided to CRS by ADHS.
- We have many specific questions we are trying to answer as it relates to the cyshcn national survey and specific program questions.
- What services are being provided, effectiveness of services, and family involvement.

WHO DO YOU BELIEVE SHOULD BE KEY PARTNERS IN DEVELOPING AN INTEGRATED SERVICE DELIVERY SYSTEM FOR CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS? ALSO DESCRIBE WHY THEY SHOULD BE KEY PARTNERS.

- Parents, individuals with these needs, private and hospital-based medical providers, therapists, and governmental agencies.
- Parents, education, child welfare, juvenile corrections, medical providers, and behavioral health.
- Governor's Office of Children, Youth, and Families, especially staff to the School Readiness Board because there should be some ability to incorporate what this Board has done around systems for early childhood.
- Academy of Pediatrics, Association of Family Physicians, schools, and child care organizations.

- Health, social services, individuals with special needs, state agencies, and research centers.
- Members of the Task Force, parents of youth involved in the state's systems, providers, RHBAs, and youth.
- Families, youth, ADHS (CRS and behavioral Health), AHCCCS, and DDD.
- ADHS, Governor's Office, Value Options, AHCCCS, DES, School Board, Superior Court, health providers from multiple disciplines.
- DES (AzEIP, DDD, Child Care, DCYF, DBME, and DCSE), Governor's Office (School Readiness Board and Office for Children, Youth, and Families), ADHS (BHS, OCSHCN, and OWCH), ADE (Early Childhood Section and Exceptional Student Services), ASDB, AHCCCS, Arizona Academy of Pediatrics, Raising Special Kids, Interagency Coordinating Council, Governor's Council on Developmental Disabilities, Children's Action Alliance, Medical Home Projects, Non-profits, Faith-based communities, and the School of Medicine.
- CYSHCN, the families/caretakers of children and youth with special health care needs, primary care providers (pediatricians, family practice, internal medicine physicians, nurses, and various therapists), a variety of medical specialists, durable medical equipment and supply companies, school officials (from K-12, college, trade, and technical schools), job training programs, transportation representatives (from city or county, especially in regards to public transportation), health insurers and health department representatives, community leaders, pharmaceutical company representatives, community organizations that are involved with children and youth with special health care needs, and industry leaders.
- Those on the Task Force are excellent.
- The current membership seems appropriate.
- Key partners appear to be involved.

DO YOU OR YOUR ORGANIZATION HAVE EXISTING PARTNERSHIPS WITH OTHER ORGANIZATIONS THAT MIGHT BE USEFUL TO USE AS CASE EXAMPLES OF INTEGRATION ACTIVITIES?

- The Indian Health Service has many partnerships and collaborations. However, I don't know t hat we specifically have case examples of integration. In the area of children and youth with special healthcare needs, some of the diabetes programs might be case examples, but they do not usually target children and youth.
- AzEIP/DDD, DDD/SBHS, DDD/ACYF
- Title V
- DDD and CPS
- Yes, with Child Help USA, to provide health-related evaluations for children who are abused or suspected of being abused.
- Out Department continues to improve our working relationships with other state agencies.
- Numerous state level agency partnerships are in place.

- We could present Utah's experience with adopting the interagency integrated Universal Application System. We can also provide case examples from Oregon and Indiana which are also adopting this system.
- Our participation with United Way agencies in piloting the use of child care health consultants and quality rating system demonstrate integration.
- Partnerships with the AZ Chapter of the Academy of Pediatrics on several projects: Quality Improvement Project, Web-based links, and including pediatricians (and residents) in training child care providers on health and safety topics—with the eventual goal of connecting the two at the local community level to encourage communications and mutual sharing/referral..

WHAT DO YOU FEEL ARE THE MOST IMPORTANT DATA TO COLLECT AND REPORT ON TO ANSWER THE QUESTION, "ARE CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS AND THEIR FAMILIES RECEIVING INTEGRATED COMMUNITY-BASED SERVICES THAT ARE EFFECTIVE IN MEETING THEIR NEEDS AND ARE THEY SATISFIED WITH THE SERVICES."

- No Response = 4
- This is a difficult set of questions to answer. Integrated community-based services are never going to happen in many communities because of resource restrictions particular to the current system. So if you ask the above question of those communities (as ADHS did in some of its focus groups), no one will be satisfied with the status quo. That being said, I am not sure how to articulate the correct question. It might be something like, "Given the reality of out current restricted resource base, does the system effectively deliver care that provides positive outcomes for children?"
- A survey from families. Maybe you could do a survey at the beginning of the grant and one at the end to see the difference. Nobody has the right to answer this question except families and youth.
- First, carefully define: "integrated community-based services," "effective," and "satisfied."
- The 2001 National Survey of Children with Special Health Care Needs is a good starting point. I believe in our planning sessions, some of weaknesses were also discussed as well and a review of those deficiencies may suggest areas for additional data to collect and report.
- Some outcome in terms of the development of children within their family context.
- Satisfaction of families with their interaction with systems of care.
- What services are being provided? Are the services appropriate? How and who funds these services? What needs to be provided and is not being provided? Why Not? How can community-based services be integrated?
- Data needs to identify (1) timeliness and ease of access, (2) responsiveness to family priorities and meaningful outcomes, (3) impact on the family and caregiver confidence and competence in supporting their child, (4) impact on child's participation in daily activities, and (5) coordination of planning and implementation to achieve functional outcomes.
- This is a broad, multi-part question. I personally am a fan of utilization-focused evaluation developed by Michael Quinn Patton. In a nutshell, collect data designed to answer specific research questions that will allow your agenda or action plan to move

forward. Large questions such as above are better tied to philosophical discussions and are not necessarily tied to the reality of a given situation.

- We have a family Satisfaction Survey that I can share.
- I don't know if I am at the end of a long questionnaire, and therefore not thinking well any more or if this is a topic that has so many tributaries of data that it is hard to express in this medium. I look forward to hearing from the data miners as to which tributaries are the highest priority for the targeted population.
- Outcomes data, functional status